

Disability stigma in the Inclusion Works programme countries: an overview of the evidence

Brigitte Rohwerder

18.11.19

This report draws on and expands previous work by Brigitte Rohwerder looking at disability stigma in developing countries (written for K4D) and information on stigma in the situational analyses and labour market assessments of the four Inclusion Works¹ programme countries. It should be noted that specific searches were not made relating to tackling stigma or stigma interventions in each of the countries so the information on tackling stigma in each of the countries is not exhaustive or necessarily representative of what is being undertaken in the countries.

1. Disability stigma²

Stigma³ arises when elements of labelling, stereotyping (negative evaluation of a label), and prejudice (endorsement of the negative stereotypes) combine to lead to status loss and discrimination for the stigmatised individual or group, and occur in situations where they are disempowered (Scior, 2016, p. 5; Mostert, 2016, p.6-8; Cross et al, 2011b, p. 65; Stuart et al, 2012, p. 6; Werner et al, 2012, p. 749). Stigma elicits negative attitudes and responses such as pity, anxiety, avoidance, hostility, bullying, withholding help, and even hatred and disgust (Scior, 2016, p. 5; Werner et al, 2012, p. 749; Sheehan & Ali, 2016, p. 106). It can lead to discrimination and abuse against people with disabilities.

At the individual level, public stigmatisation and discrimination can result in internalised oppression, loss of self-esteem, and feelings of shame as people with disabilities may have to

¹ Inclusion Works is a £12.8m consortium led programme, which brings together an experienced and diverse range of partners who, through strong collaboration, will create and test innovative approaches to improve the long-term economic empowerment and inclusion of people with disabilities in Bangladesh, Kenya, Nigeria and Uganda.

² Expanded and adapted from: Rohwerder, B. (2018). *Disability stigma in developing countries*. K4D Helpdesk Report 312. Brighton, UK: Institute of Development Studies.

³ There are some who argue that stigma is not a helpful term to use. Stigma is a broad term, which can create ambiguity in its use (Peters, 2015, p. 247). Harris (in Peters, 2015, p. 248) also notes that there is a risk that using the word stigma as synonymous with negative experience could 'contribute to these negative outcomes by validating the perspectives of the stigmatiser; rendering the stigmatised voiceless, subordinate and invisible and denying the possibility of alternative outcomes'. However, Peters (2015, p. 249) argues that the concept of stigma is important for contributing to the reduction of all the negative consequences associated with stigma, although people should be 'more careful how they apply the concept of stigma, write and talk about those affected by stigma in a thoughtful and dignified way and be aware of the role they play in transmitting this message'.

face great challenges in overcoming the negative views of their community or societies to achieve self-acceptance and a sense of pride in their lives (DSPD, 2016, p. 6; Bond DDG, 2017, p. 4). This is known as internalised or self-stigma and can have negative effects on physical and psychological health (Cross et al, 2011b, p. 63, 66-67; Stuart et al, 2012, p. 8). Self-stigma also consists of stereotypes (e.g. 'I am a weak person' or 'I am incapable') as people with disabilities internalise the negative attitudes of others; which in turn can lead to self-prejudice in the form of negative emotional responses (low self-esteem or self-worth); which can lead to self-discrimination through behavioural responses (not seeking employment opportunities or avoiding social relationships) (Sheehan & Ali, 2016, p. 91-92). Self/internalised stigma can increase people's disability (Cross et al, 2011b, p. 65). Fear or anticipation of stigma can lead to non-disclosure avoidance of potential situations of discrimination, which can also have a disruptive impact on people's lives as they live in anticipation of harmful effects (Cross et al, 2011b, p. 66, 69; Sheehan & Ali, 2016, p. 92). However, it is important to note that 'individual reactions to stigma vary, ranging from significant loss in self-esteem to righteous anger', or even neither (Werner et al, 2012, p. 750).

Stigma can extend by association to family members, who may experience stress (by feeling shame, guilt, and worry) as a result, which can reduce their reserves and undermine their ability to provide the social supports to their disabled family member (Stuart et al, 2012, p. 6, 11-12).

Organisations working with people with disabilities have found that stigma often lies at the root of the discrimination, exclusion and low status, experienced by people with disabilities and their families in all aspects of their lives in low and middle income countries (Bond DDG, 2017, p. 3; DSPD, 2016, p. 6; Mostert, 2016, p. 5, 11). Combined with poverty and other barriers, stigma and discrimination put people with disabilities' rights at risk (Inguanzo, 2017, p. 7). Higher levels of stigmatising behaviour have been found to be 'associated with higher levels of psychological distress (symptoms of depression and anxiety) and a lower quality of life' (Sheehan & Ali, 2016, p. 105).

Factors which contribute to disability stigma

Lack of understanding and awareness regarding the causes of disabilities and their resulting characteristics is a key factor in the stigma experienced by people with disabilities (Mostert, 2016, p. 9; DSPD, 2016, p. 5; Stone-MacDonald & Butera, 2014, p. 6). Disability is often blamed on misdeeds of ancestors; misdeeds of parents (mainly mothers); misdeeds of the person with disabilities; supernatural forces such as demons/spirits; witchcraft; or punishment or fate from God (DSPD, 2016, p. 5; Aley, 2016; Mostert, 2016). Misconceptions about the cause of disabilities often result from cultural or religious beliefs (Bond DDG, 2017, p. 3). For instance, a literature review looking at journal articles examining cultural beliefs and attitudes about disability in East Africa found that traditional beliefs about the causes of disability continued to be prevalent (Stone-MacDonald & Butera, 2014, p. 5). People often combined different beliefs about causes of disability, for example suggesting a medical explanation in addition to religious understandings (Stone-MacDonald & Butera, 2014, p. 5). Misconceptions about disability are often reinforced by ill-informed and insensitive media coverage that perpetuates negative views of disability (DSPD, 2016, p. 5).

As a result of these beliefs, people with disabilities may be thought to be not quite human or a source of shame, which has serious consequences for how they are treated. Lack of understanding about why their child is born with an impairment and beliefs that it means the family is being punished or under some form of curse or that the child is a non-human spirit has been found to result in the infanticide of new born children with disabilities in some countries

such as Kenya⁴, Guinea, Niger, Sierra Leone, and Togo, and Nepal (Inguanzo, 2017, p. 20, 32, 34; Njelesani et al, 2018, p. 5; Mostert, 2016, p. 9, 12; Parnes et al, 2013, p. 25-26, 33). However, there is no data on the prevalence of infanticide of children with disabilities as it is a very sensitive issue and often occurs in secret (Inguanzo, 2017, p. 20; Njelesani et al, 2018, p. 6). The stigma associated with the birth of a children with disabilities can lead to fathers abandoning the family, with the mother left with the sole responsibility for care (Ditchman et al, 2016, p. 32; Aley, 2016, p. 15; Parnes et al, 2013, p. 26). The stigma faced by children and adults with disabilities mean they face a greater risk of violence, abuse and neglect than their non-disabled peers (Njelesani et al, 2018, p. 4, 6; Parnes et al, 2013, p. 9; Aley, 2016, p. 16). The belief that some people with disabilities aren't human explains why treating people with disabilities in inhumane ways can go uncontested in some communities (Aley, 2016, p. 15). Traditional beliefs can result in violent "cures", for example, practices of forcible ingestion of contaminated water or other substances for psychosocial disability or epilepsy (DSPD, 2016, p. 7).

The low numbers of people with disabilities in national censuses or official statistics is often attributed to stigma around disability, with children with disabilities going unreported and unregistered, affecting their access to services (Inguanzo, 2017, p. 31; Bond DDG, 2017, p. 3; Parnes et al, 2013, p. 25). The stigma around disability can sometimes cause the rejection or ostracism of people with disabilities and their whole family (Inguanzo, 2017, p. 20; Parnes et al, 2013, p. 8). When disability is associated with punishment for previous immorality it can be met with strong social disapproval, for example (Aley, 2016, p. 15). As a result people with disabilities may never leave their homes or are sent away to institutions in order to avoid being seen by the community, as the community believes that the family has done something wrong or is under some form of curse (Inguanzo, 2017, p. 20-21, 26).

However, not all cultural beliefs result in negative beliefs about disability and some communities in Africa perceive some disabilities positively, with many families taking good care of their children with disabilities (Mostert, 2016, p. 9, 16; Stone-MacDonald & Butera, 2014, p. 9; Groce & McGeown, 2013, p. 7).

Lack of understanding and awareness about the nature and abilities of people with disabilities, also contribute to the stigmatisation, discrimination and abuses they experience. Stigmatisation of disabled people can occur because of the expectation that people with disabilities are less able to contribute to the good of the family and the community, and the assumption that they are a burden (Mostert, 2016, p. 17; Aley, 2016, p. 15, 18). Low expectations as to the potential abilities of people with disabilities can prevent children with disabilities from attending school (DSPD, 2016, p. 6; Ditchman et al, 2016, p. 34; Parnes et al, 2013, p. 27; Inguanzo, 2017, p. 27; Aley, 2016, p. 17). Being excluded from school in this way curtails children with disabilities' future life chances, which can result in a 'reinforcement of the communities' commonly held beliefs that persons with disabilities are dependent and non-productive' (Aley, 2016, p. 17).

Stigma and beliefs about the nature of disability can also restrict people with disabilities' ability to develop relationships (Franklin et al, 2018, p. 5). Women with disabilities can struggle to access sexual and reproductive health services due to cultural beliefs that they are not sexually active, despite being more likely to be a victim of sexual abuse than their non-disabled peers (Rugoho & Maphosa, 2017, p. 1-2). Disability and gender stereotypes assume that women with disabilities are 'undesirable, unworthy and incapable of love and sexual expression' (Ando, 2017, p. 4).

⁴ For example "there is a big problem in the Maasai community because when a family discover they have a child with a disability, sometimes they end up killing that child, because they fear the stigma of the community, [...] because the community believes the disability is a curse" (Inguanzo, 2017, p. 20).

Sexual abuse is sometimes considered a 'favour' to people with disabilities because it is assumed that it is the only way they will experience sex (Aley, 2016, p. 21, 31). On the other hand, it is reported that some African communities perceive people with disabilities as hypersexual and believe that discussing sexual and reproductive issues with them would trigger their sexual feelings and they would not be able to control their sexual desires (Rugoho & Maphosa, 2017, p. 2). In countries where there is a common folk belief that sex with a virgin can cure HIV, the often incorrect assumption that people with disabilities are sexually inactive, puts them at risk of such rapes (DSPD, 2016, p. 7; Aley, 2016, p. 22). The assumption that people with disabilities will be virgins and therefore free of other sexually transmitted diseases also makes them vulnerable to assailants who assume they are safe sexual partners (Aley, 2016, p. 31). Social attitudes and understanding of disability and sexuality in general were found to be strong influencing factors on the risks that persons with disability face in relation to sexual abuse in East Africa (Aley, 2016, p. 6, 14). Girls with disabilities, especially those with intellectual, communication, or visual impairments, are especially vulnerable as a result of assumptions that they will not be able to tell others about what happened to them and denounce the perpetrators (Inguanzo, 2017, p. 21; Aley, 2016, p. 28-29). The dehumanisation of children with intellectual disabilities and the assumption that they are unable to understand what is happening to them can also make people more willing to accept behaviour that would be impermissible otherwise (Ditchman et al, 2016, p. 33). The stigma and shame associated with sexual abuse in general in some communities can be another factor in underreporting of sexual abuse against persons with disabilities, with discussions about sexual matters combined with disability issues considered particularly uncomfortable or taboo in East Africa for example (Aley, 2016, p. 32-33).

Communities may shun people with disabilities and their families because they believe they will spread their 'ill fortune' to others either intentionally or unintentionally (Groce & McGeown, 2013, p. 5). People with disabilities are sometime avoided by pregnant women out of fear that their unborn child will be contaminated (Njelesani et al, 2018, p. 4). Parents of non-disabled children are reported to sometimes believe that children with disabilities will "infect" the classroom and do not want their children to associate with children with disabilities (Parnes et al, 2013, p. 27).

In some urban areas of Africa, unscrupulous urban practitioners of 'witchcraft' or 'magic'⁵ have been reinterpreting traditional links between disability and witchcraft, using practices, which could involve abuse, mutilation or killing of persons with disabilities to obtain body parts for use in rituals, potions or amulets with the promise to help individuals become wealthy, gain social prominence, succeed in love or vanquish rivals (Groce & McGeown, 2013). The links between disability and witchcraft are encouraged by some Pentecostal churches 'where disability is linked to evil spirits or the devil, while 'cure' of disability is linked to virtue and prosperity' (Groce & McGeown, 2013, p. 3, 20). People with disabilities, especially children with autism and people with mental illness, are particular targets of witchcraft accusations, due to their low social status but also because of others' interest in acquiring their property, money or land (Groce & McGeown, 2013, p. 15).

Discriminatory legislation and policies also reinforce prejudice and discrimination, while the segregation of people with disabilities perpetuates negative stereotypes and limits their quality of life and potential to contribute to society (DSPS, 2016, p. 5; McConkey, 2018, p. 6-7; Scior et al, 2015, p. 101). Stigma can contribute to the lack of adequate services for disabled people,

⁵ 'These new urban witchdoctors tend to be self-appointed experts, although the amount of training they have varies. Their background is distinct from traditional healers who undergo intensive training in an established body of knowledge and whose practices are situated within the bounds and under the oversight of a coherent cultural tradition' (Groce & McGeown, 2013, p. 9).

‘resulting in poorer treatment, rejection, and devalued roles within society’ (Werner et al, 2012, p. 750).

Differences in the extent of stigmatisation

Attitudes towards disability are not the same within countries, communities, or even families (DSPD, 2016, p. 3; Groce & McGeown, 2013, p. 6). In many cases, negative beliefs about disability differ based on the types of impairment and how/when the disability was acquired (DSPD, 2016, p. 5; Bond DDG, 2017, p. 4). Cultural barriers are usually worse when a child is born with an impairment because of beliefs that the family has done something wrong or that they are under some form of curse (Inguanzo, 2017, p. 26). The degree of stigma also differs between visible and stable disabilities and disabilities that are invisible and variable (Inguanzo, 2017, p. 11). People with intellectual disabilities, severe mental health conditions, albinism, and sensory disabilities are often more stigmatised than people with physical disabilities (Scior, 2016, p. 6; Bond DDG, 2017, p. 4; Parnes et al, 2013, p. 26). People with disabilities who can participate in their communities experience less stigma than those with more severe disabilities (Mostert, 2016, p. 11; Parnes et al, 2013, p. 26; Stone-MacDonald & Butera, 2014, p. 7, 10). For example, Stone-MacDonald and Butera (2014, p. 10) found that in East Africa it ‘appears that individuals with disabilities are less likely to experience stigma associated with an obvious physical deformity or a diagnostic label and more likely to face discrimination if they are unable to participate in the daily social and economic activities of the community than their counterparts in the developed world’.

Females who are disabled are doubly disadvantaged, due to the stigma associated with gender as well as disability (Mostert, 2016, p. 10-11; Bond DDG, 2017, p. 4). People with disabilities from minority groups can also face additional discrimination on ethnic grounds (Inguanzo, 2017, p. 27). Socio-economic issues can also affect attitudes towards disability; for example, poorer people with disabilities may face more stigma than more economically advantaged people with disabilities (DSPD, 2016, p. 5). People with disabilities in rural areas may experience more harmful practices than in urban areas (Inguanzo, 2017, p. 34; Njelesani et al, 2018, p. 6).

Measuring stigma

In order to examine the extent and severity of stigma, researchers need accurate measurement tools (Werner, 2016, p. 15). Measurement of stigma is a challenge (Cross et al, 2011b, p. 64). Specific tools for different disabilities are needed because stigma may differ across disabilities, yet the attention paid to the measurement of different disability stigma has not been even (Werner, 2016, p. 15). A lot of existing scales focus on measuring stigma around mental illness (Werner et al, 2012, p. 751). A number of scales measure attitudes (consisting of cognitive, affective, and behavioural components), but these do not capture the entirety of stigma (the chain from stereotypes through prejudice to discrimination) (Werner, 2016, p. 16). Scales can address external (public), self, or family stigma (Werner et al, 2012, p. 751). Most scales have been developed and used predominately in Western countries, and some had their last reported usage a decade ago (Werner, 2016, p. 16; Werner et al, 2012, p. 759).

Examples of stigma measures

Werner et al (2012, p. 753, 760) conducted a systematic review of stigma measures relating to intellectual disability and found that most of the scales reviewed were based on public “attitudes” rather than specifically addressing stigma, while fewer measured self-stigma, and even fewer measured family stigma. Existing scales intended to measure attitudes toward general disability

groups include 'the Semantic Differential Scale (Osgood, Suci, & Tannenbaum, 1957), the Scale of Attitudes toward Disabled Persons (Antonak, 1982, 1988), the Attitudes Toward Persons with Disabilities Scale (Yuker, Block, & Campbell, 1960), the Interaction with Disabled Persons Scale (Gething, 1994), and the Multidimensional Attitudes Scale (MAS, Findler, Vilchinsky, & Werner, 2007)' and the Attitudes to Disability Scale (ADS; Power, Green, & the WHOQOL-DIS Group, 2010) (Werner et al, 2012, p. 751, 753).

The Attitudes to Disability Scale (ADS)

The Attitudes to Disability Scale (ADS) was developed in conjunction with focus groups of people with physical and intellectual disabilities and tested in 12 centres throughout the world (Power et al, 2010). The scale can be used with individuals with disabilities ('personal' form of the scale) and with the general population to look at attitudes towards disability ('general' form of the scale) (Power et al, 2010, p. 872). The scale focuses primarily on four different aspects of disability: issues of inclusion and exclusion and burden on families and on society as a whole; discrimination; positive gains in relation to self and to others; and current and future hopes and prospects and whether or not disability impacts on these hopes (Power et al, 2010, p. 873-874). Werner et al (2012, p. 753) found it to be the most comprehensive scale in their review.

Social distance scales

Social distance is the willingness of an individual to have social contact with a member of another group, in situations of varying degrees of intimacy (Werner, 2016, p. 21). Many researchers have used some form of social distance scale to measure external stigma (Werner, 2016, p. 21).

The ID Stigma Scale

The ID stigma scale was developed by Werner and includes 35 items measuring cognitive, affective, and behavioural reactions when meeting a man with an intellectual disability described in a vignette (Werner, 2016, p. 19). The scale consists of three dimensions: stereotypes (including acceptance, low ability, and dangerousness); prejudice (including negative affect and calm affect); and behavioural (including withdrawal, social distance, and helping) (Werner, 2016, p. 19). In order to combat the effects of social desirability, the ID stigma scale had been adapted to an indirect version, where participants are asked to report on the reactions they believe another person would have (Werner, 2016, p. 19). As it is relatively new, the scale has not been used much, although it is based on the widely used Multidimensional Attitudes Scale (Werner et al, 2016, p. 20).

2. Disability stigma in Bangladesh⁶

Persons with disabilities are often subjected to discrimination and negative attitudes in Bangladesh, where they live in an unfriendly and hostile environment. They encounter non-cooperation, ill treatment, neglect and hostility at the family, community, society and government levels (Sultana, 2010). A study that examined the impact of disability on the quality of life of disabled people in rural Bangladesh reported that more than half of people with disabilities were looked at negatively by society. Disabled women and girls experienced more negative attitudes than their male counterparts (Hosain, Atkinson & Underwood, 2002). Discrimination, exclusion

⁶ Taken and adapted from: Thompson, S. (2019). *Bangladesh Situational Analysis*. Disability Inclusive Development and Thompson, S. (2019). *Bangladesh Situational Analysis*. Inclusion Works.

and neglect of persons with disabilities and their households are still prevalent, as the laws (including the Disabled Persons Protection and Rights Act 2013) are not being sufficiently enforced (GED, 2015).

Titumir and Hossain (2005) state that many people in the Bangladesh view disability as a curse and a cause of embarrassment to the family. Women with disabilities are particularly vulnerable to social discrimination and neglect. Research by Quinn et al (2016) to document the experiences of 15 women with disabilities in Bangladesh found that they had been subject to oppression due to beliefs regarding traditional gender roles and the common perception that women with disabilities do not need to be educated. Discrimination from their local community was reported by the majority of the women. All of them attributed this to a poor understanding of disability, leading to misconceptions that women with disability were 'cursed' or had committed an offence against God. This form of exclusion was found to impact significantly on their mental health, resulting in reports of depression. Drawing on research by Hosain, Atkinson and Underwood (2002), Kandasamy, Soldatic and Samararatne (2017) explain that in Bangladesh, disability is not the primary disadvantage for women in rural areas, rather, their disability becomes an additional burden in their already marginalised gender position. Ethnicity, social class and race become highly contingent factors that shape women's experience of living with a disability in contexts like Bangladesh. With regards to children with disabilities in Bangladesh, discrimination in the family, the community and the workplace is at the core of most rights violations (UNICEF, 2014).

Persons with disabilities are usually left out of development due to inadequate understanding and awareness among the general population and also the people who design and manage developmental programmes. They are often not aware of the extreme difficulties faced by persons with disabilities and most do not have access to gain the skills and knowledge that would enable them to include persons with disabilities and their families in development programmes. The neglect that results from this lack of knowledge reinforces and multiplies the effects of the negative attitudes that already exist within families and communities. Most of the time it is not the impairment rather the attitudinal and environmental factors that a person with disabilities encounters in everyday life that cause his or her exclusion from society (CAMPE, 2011).

The belief that disability is a curse and a punishment for sinful behaviour permeates all levels of society and affects access to adequate care, health services, education and participation. Negative attitudes of the family, teachers and community are a factor in the lack of school enrolment of children with disabilities (CAMPE, 2011). Huq et al (2013) found that distance, cost, and stigma mean that assistive devices such as hearing aids are difficult for rural residents to access. Women with disabilities have poor health outcomes within a gender-biased cultural context due to ill-informed attitudes and routine discrimination against them across Bangladeshi society (Quinn et al, 2016). A study found that families arranged marriages for their daughters with disabilities with whoever accepted them because of the low expectations they had for them (Ando, 2017, p. 2).

However, not all people have negative attitudes towards people with disabilities. Examining the views of 2,400 participants, Titumir and Hossain (2005) reported that 55% of respondents accept persons with disabilities well and 20% give extra privilege to them. Most of the participants would be comfortable having friendships with people with disabilities but would never marry them. 63% of respondents do not believe that persons with disabilities are a burden to the family. Most of the people argued that persons with disabilities should get extra assistance in society including in the transport, health, and education sectors.

Disability stigma and employment

The main barriers to employment for persons with disabilities in Bangladesh seem to be prejudice and ignorance (Danish Bilharziasis Laboratory, 2004). Research carried out during the labour market assessment with disabled people's organisations (DPOs) noted that major barriers to inclusive employment included social stigma (Huda et al, 2019, p. 83). This manifested itself in a variety of ways, including family members of persons with disabilities not allowing them to come out and join the labour force; the assumptions from employers that persons with disabilities are unable to do the work required; and co-workers and security guards misbehaving with disabled workers (Huda et al, 2019, p. 83-84).

Some people with disabilities reported not applying for work as they felt they would be rejected because of their disability (Huq et al, 2013). The alternative report on the status of implementation of the CRPD reported that the situation with regards to persons with disabilities and inclusive employment is not acceptable. Employees with disabilities commonly face bullying, harassment and misbehaviour at work and tend to get paid less than others, particularly in manual or field-based jobs (CRPD Alternative Report Platform, 2019). In most cases, employees with disabilities do not get equal rights and privileges as their colleagues without any disability (Ali, 2014). NGDO et al (2015) reported that in Bangladesh 72% of respondents in a survey reported that workers with disabilities tend to get paid less than others, especially in manual jobs. In Bangladesh, persons with leprosy related disabilities in particular are often discriminated against and refused employment largely on account of stigma associated with leprosy (TLMB, 2019). Women with disabilities' access to employment was impacted by perceived inefficiencies of women with disabilities as compared to women without disability and particularly men (with or without disability) (Quinn et al, 2016).

Tackling disability stigma

In May 2019, the Committee on the Rights of Persons with Disabilities requested Bangladesh to deliver information on measures undertaken to combat stereotypes, prejudices and harmful practices relating to persons with disabilities in all areas of life, including discrimination against persons with disabilities belonging to minority communities and indigenous peoples and persons affected by leprosy (UN, 2019). In Bangladesh, there have been only a few systemic interventions to raise awareness of persons with disabilities at the community level. While progress is slow, changes have been noted due to policy modifications and social mobilisation. For children with disabilities this includes increased access to school and to opportunities for skills development and employment. Now that they are seen as contributors rather than burdens, their status in the family and the community is improving (UNICEF, 2014).

Gender specific, local disability support has been shown to facilitate employment and protect women from discrimination in the work force. Women also reported that the environmental accessibility and inclusive community attitudes contributed to their success at work and social life, as well as to improved mental and physical health (Quinn et al, 2016). Staff orientation and training on disability issues in the workplace should be provided to ensure empathy and sensitivity towards colleagues with disabilities (CRPD Alternative Report Platform, 2019).

3. Disability stigma in Kenya⁷

People with disabilities in Kenya face stigma and discrimination that lead to enduring and humiliating stereotypes and prejudices against people with disabilities as a curse and a burden on society, as well as undermining the human right principals which are key to inclusion (Sightsavers, 2018, p. 4; KNCHR, 2016, p. 16, 21; Kabare, 2018, p. 10). Aley's (2016, p. 14) study⁸ in Kenya (and Uganda) found that respondents felt that attitudes to disability in their community were overwhelmingly negative due to 'harmful traditional beliefs and misconceptions about the causes and nature of disability and about what roles and rights persons with disabilities can have in society'. Many communities believed that disability was a curse resulting from transgressions of former generations in the family (Aley, 2016, p. 14). Wrongdoing of ancestors which results in disability is usually placed on the mother's side of the family rather than the fathers (Aley, 2016, p. 15). Many Kenyans believe that disability is the result of taboo activities such as adultery or incest, or broken taboos by the mother (such as eating eggs during pregnancy or lying on her stomach) (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24). Within different communities in Kenya some beliefs are more specific, for example, 'among the Nandi, killing an animal without provocation during a wife's pregnancy is believed to cause disability in the new-born child, while among the Abagusii, children born with cleft palates are thought to be the result of parents making fun of someone with a disability' (Mostert, 2016, p. 16; Stone-MacDonald & Butera, 2014, p. 5-6). Some communities believed that people became disabled because they had caused accidents and not been properly cleansed (Aley, 2016, p. 14). Others believe that disability is a curse from a supernatural or mysterious otherworldly force (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24). Still others believe that disability results from witchcraft spells placed either upon the family or the individual with disabilities (Mostert, 2016, p. 16; McConkey et al, 2016, p. 184; Parnes et al, 2013, p. 24).

However, not all traditional beliefs are negative. For example, the Turkana of Kenya perceive children with disabilities as a gift from God to be well taken care of, or else they risk the wrath of the deity (Mostert, 2016, p. 9; Stone-MacDonald & Butera, 2014, p. 7). Aley (2016, p. 20) found that respondents reported that some community members who would refer to disability in the context of the teachings of their faith and frequently viewed persons with disabilities more positively and as individuals who should be allowed to take their place in the community and be more socially included (although others believe that God imposes disability as a punishment or to prevent them from sinning).

In many communities, families hide away their disabled family member, especially children, due to societal stigma (Kabare, 2018, p. 10; Rodríguez et al, 2018, p. 5). Bunning et al (2017, p. 13) found that the stigma associated with people with disabilities extended to people who helped them, and it was felt that 'the person offering assistance would also "...give birth to such a child"'. Stigma excludes people with disabilities from economic and social activities thus trapping them in a cycle of poverty (Jillo, 2018, p. 3; Bunning et al, 2017, p. 15). People with intellectual disabilities, psychosocial disabilities, albinism, as well as women and girls, older persons,

⁷ Taken and adapted from: Rohwerder, B. (2019). *Kenya Situational Analysis*. Disability Inclusive Development; and Rohwerder, B. (2019). *Kenya Situational Analysis*. Inclusion Works.

⁸ Qualitative participatory action research in Uganda and Kenya with service providers and key responders. Involved 52 individual interviews and 9 focus groups.

children and youth with disabilities, are particularly affected by stigma and discrimination (Sightsavers, 2018, p. 5; Jillo, 2018, p. 3; CRPD, 2015, p. 3-4; KNCHR, 2016, p. 48, 75).

More affluent social classes have the advantage of being able to pay for support and were found to be 'more likely to support their children with disabilities properly and to promote their education and social inclusion, rather than hiding them away or believing in harmful traditional practices' (Aley, 2016, p. 16).

Relationships between people with disabilities or between someone with a disability and someone without a disability were frequently regarded by others with suspicion, mistrust, and ridicule (Aley, 2016, p. 23). Communities may believe that people with disabilities lack the necessary qualities to make successful marriage partners (depending on the disability type), and beliefs around disability being related to bad family spirits can lead to concerns that they will bring evil or misfortune with them if they marry into the family (Aley, 2016, p. 24-25). Sometimes men form sexual relationships with women with disabilities but are unwilling to be seen with them in public due to fear of the community's reaction (Aley, 2016, p. 23). There may be concerns that relationships between people with disabilities and someone without disabilities are not consensual relationships due to the assumption that people with disabilities cannot form their own relationships (Aley, 2016, p. 23). Other myths exist concerning the perceived benefits of having sex with people with disabilities, such as that it will bring good luck (Aley, 2016, p. 22, 31).

Disability stigma prevents persons with disabilities' full participation in life. Stigmatisation has been identified as a factor in the high dropout rates of children with disabilities from schools (DoE, 2018, p. 11). The main challenges relating to access and equity in the provision of education and training to children with disabilities include, amongst others, cultural prejudice and negative attitudes (DoE, 2012, p. 49; Sightsavers, 2018, p. 8; DoE, 2018, p. 8; KNCHR, 2016, p. 49; Kabare, 2018, p. 10; Kiru, 2019, p. 184-185). Women and men with disabilities encounter barriers to accessing quality healthcare, including reproductive health, as a result of insensitivity and negative attitudes of health care workers among other factors (KNCHR, 2016, p. 40, 75, 84, 159; Kabia et al, 2018, p. 1). A study in 2014 in Kakuma Refugee Camp also found that refugee women and adolescents with disabilities lacked access to sexual reproductive health services and faced stigmatisation from health workers (KNCHR, 2016, p. 78).

Children with disabilities

Children with disabilities have been abandoned by their families and negative stereotypes against them exist, especially in rural areas (CRPD, 2015, p. 3; Bunning et al, 2017, p. 13; KNCHR, 2016, p. 75; Rodríguez et al, 2018, p. 4). Children with disabilities in rural areas and those among minority communities are particularly inhibited by negative cultural practices such as female genital mutilation and disinheritance of persons with disabilities (Inguanzo, 2017, p. 34).

Children with disabilities are thought to be 'cursed, bewitched, and possessed' and a punishment for the sins of the mother (Rodríguez et al, 2018, p. 4). A recent investigation by Disability Rights International found that parents are even placed under enormous pressure to kill their children with disabilities (Rodríguez et al, 2018, p. 4). '37% of the women surveyed from Nairobi said they were pressured to kill their children with disabilities while 57% of women from the more rural areas felt pressure to kill their children'⁹ (Rodríguez et al, 2018, p. 4). Mothers of children with disabilities are sometimes thought to be cursed too and bring shame to their families and

⁹ Approximately 90 mothers were questioned (Rodríguez et al, 2018, p. 4).

communities as a result of their children (Rodríguez et al, 2018, p. 5). Many women who give birth to children with disabilities are rejected by their husbands and wider families, which means they and their children lead lives of social isolation (Rodríguez et al, 2018, p. 5). If they lack support it is very hard for mothers of children with disabilities to survive, which makes infanticide seem like an option (Rodríguez et al, 2018, p. 5).

Children with disabilities who live in orphanages were found to be living in overcrowded and filthy conditions, with children spending lengthy times in restraints and isolation rooms, and an overall lack of staff and untrained staff, neglect, and the withholding of medical care (Rodríguez et al, 2018, p. 6). Disability Rights International has also documented severe neglect, physical and sexual abuse, and torture in Kenya (Rodríguez et al, 2018, p. 6). Many of these children are not actually orphans but the 'belief by families that their children will be better off in institutions – that they will be well-fed, given an education, or have access to rehabilitation for a child with a disability - drive them to give up their children' (Rodríguez et al, 2018, p. 7).

Women with disabilities

Women in Kenya 'face a number of challenges including the fact that they have limited access to and control of resources and other socio-economic opportunities; they have lower literacy levels compared to men; fewer of them enrol in mainstream education; they are generally poorer than men; fewer of them are in formal employment compared to men; where they do work then it is under deplorable conditions; they earn lower incomes; they have poor access to quality healthcare and advice on family planning; and are more vulnerable to gender-based violence' (KNCHR, 2016, p. 39). The situation is even worse for women with disabilities due to the marginalisation, stigma, and double discrimination they experience and the negative cultural practices and attitudes towards disability and gender biases (KNCHR, 2016, p. 39, 156). In addition, traditional and conservative views on the position and the role of women in society 'reinforce the misconception about the ability of women and girls with disabilities to adequately perform their roles as other peers' (KNCHR, 2016, p. 39). Women with disabilities experience high levels of gender-based violence and sexual abuse in both the public and private sphere (KNCHR, 2016, p. 40, 74, 156).

Disability stigma and employment

The Kenya National Bureau of Statistics noted that 'persons with disabilities are more likely to experience disadvantage, exclusion and discrimination in the labour market and elsewhere than persons without disability' (KNBS, 2012, p. 24). People with disabilities also experience poor remuneration and discrimination in the workplace (Kingiri et al, 2017, p. 3). Ebuanyi et al (2019, p. 1) found that persons with mental or psychosocial disabilities found it especially hard to find employment, as a result of the stigma and discrimination they faced.

Opoku et al (2016, p. 85) suggest that barriers to employment stem 'mainly from the religious, cultural, and medical perceptions of disability, leading to the discrimination and exclusion of persons with disabilities from mainstream activities'. Research with people with disabilities found that self-stigma and poor perceptions by persons with disabilities about their abilities and self-worth and ability to compete in the job market with non-disabled workers was a significant barrier to their participation in formal sector employment (Mueke, 2014, p. 39-40; Opoku et al, 2016, p. 82; KNCHR, 2014, p. 37, 40; Gesongo & Baraza, 2019, p. 6, 36). Some persons with disabilities and caregivers interviewed by KNCHR (2014, p. 37, 40) 'observed that poor perceptions by persons with disabilities about their abilities and self-worth and difficulty in socialisation as a person with disability remains the greatest hindrance to their development and subsequent

realisation of their rights' and these attitudes were identified as a barrier to their employment. Stigma and lack of support from family and communities is also felt to impact on employment opportunities as it often meant that persons with disabilities were unable to acquire the skills that would make them employable (Opoku et al, 2016, p. 84; Gesongo & Baraza, 2019, p. 6). While many persons with disabilities lack the required qualifications for formal sector jobs due to the challenges they face accessing education, even people with disabilities with university education have struggled to find employment due to employer attitudes (KNCHR, 2016, p. 87).

Stigmatisation and assumptions by employers about the capacity of persons with disabilities to deliver within workplace have also been found to be a barrier to formal employment for persons with disabilities (KNCHR, 2014, p. xii, 37; Gesongo & Baraza, 2019, p. 26). A number of 2016 studies found that negative employee perceptions, including in relation to concerns about cost and the capabilities of persons with disabilities, was a key barrier to the inclusive employment of persons with disabilities (Wanjala et al, 2016, p. 2, 8; Opoku et al, 2016, p. 77, 82; Curvers et al, 2016, p. 51; Maina, 2016, p. 87-88, 97; Opini, 2010, p. 279-280). For example, one study found that people with disabilities struggled to find employment as a result of perceptions that people with disabilities are unable to contribute, despite their impairment not impeding their ability to work (Curvers et al, 2016, p. 51; Opoku et al, 2016, p. 82). Participants in another 2016 study reported that they were 'mocked, handed cash, and turned away by employers, because employers had low expectations of them' (Opoku et al, 2016, p. 81-82). This discouraged people with disabilities from continuing to apply for jobs and some turned to begging as their only option to survive (Opoku et al, 2016, p. 82). Another study in 2016 with 38 persons with disabilities found that 87% of them reported being denied employment, most likely because of their disability (Maina, 2016, p. 96). Most had been refused a job during their job interview (Maina, 2016, p. 96). A study in 2018 looking at employer perspectives on opportunities for improved employment of persons with a mental disability found that barriers to employing persons with mental disabilities mainly included concerns that they would be unable to meet employer expectations in terms of productivity and underlying misunderstandings about mental illness leading to fears about potential violent behaviour and how to handle it in the workplace (Ebuenyi et al, 2019, p. 4-5). There were also some worries about the reactions of co-workers, customers and clients (Ebuenyi et al, 2019, p. 5). The private sector employers interviewed in 2014 identified key barriers to employment of graduates with disabilities to also include concerns that people with disabilities may not be able to do the work appropriately or competently; or that other staff may not be comfortable or like working with staff with disabilities (Mueke, 2014, p. 39-40). A focus group discussion in relation to this found that 'employers were reluctant to employ people with disabilities because they saw them as a burden and as people who would need constant attention' and they felt that they would 'not be able to provide the necessary adjustments that would enable employees with disabilities to work comfortably' (Mueke, 2014, p. 40).

Abuse and discrimination at work is also an issue. About 91% of persons with disabilities interviewed by Maina (2016, p. 96) cited high levels of negative jokes toward them, '84.8% cited that they are assigned more difficult duties; 83% indicated that they are made to do unpleasant or hazardous jobs while 76.1% cited that there are cases of threats and verbal abuse toward them by their employers, supervisors and fellow employees'. About 72% of respondents responded they are bothered, tormented or troubled to a great extent because of their status at work (Maina, 2016, p. 96). Some of the persons with disabilities interviewed by Maina (2016, p. 96) reported being given a light workload which made them feel bad about themselves. Most of this abuse and harassment goes unreported and unpunished (Maina, 2016, p. 96). 45% of the persons with disabilities interviewed by Maina (2016, p. 96) reported being fired from previous jobs due to their disabilities.

Tackling disability stigma

Existing empowerment programmes targeting these particularly stigmatised groups are insufficient (Sightsavers, 2018, p. 5). However, the government notes that there has been a 'slow but noticeable improvement in public perception towards and treatment of persons with disabilities', including in employment (KNCHR, 2016, p. 21). Respondents in Aley's study (2016, p. 20-21) noted that progressive government policy had helped to gradually change attitudes towards disability. Aley (2016, p. 14, 16) found that respondents reported that attitudes among professionals in Kenya were improving and more progressive ideas about disability are beginning to be accepted, especially amongst educated and economically mobile groups, although they often qualified this observation by stating that it will still take a long time for 'the community' to change their negative attitudes. Teachers, particularly special education teachers, were viewed as being very important in influencing attitudes for the better amongst parents (Aley, 2016, p. 16). Aley (2016, p. 18) found that contact in schools, especially where pupils with disabilities had done well and were positive role models, helped to improve attitudes towards disability.

An e-intervention in Kenya and Nigeria in 2016, that involved showing over 1000 participants a 6-minute film designed to increase awareness of intellectual disability and its causes, and to challenge stigmatising beliefs commonly found in African countries, resulted in positive changes in attitudes, while there were no changes amongst participants who had watched the control film (Odukoya & Chenge, 2017). The films used a combination of education and indirect contact to provide factual information about intellectual disability and provide first-hand accounts of the lives of people with intellectual disabilities (Odukoya & Chenge, 2017). Data was collected at three time points (baseline, immediately post-intervention and at one month follow-up) using attitudinal questionnaires (measuring cognition, affect, and behavioural intentions) to measure the impact of the film on attitudes (Odukoya & Chenge, 2017).

A study looking at the employment of persons with mental disabilities found that employers were more likely to employ persons with disabilities due to their individual skills or if they knew them/were familiar with their mental illness (Ebuenyi et al, 2019, p. 5-6). Ebuenyi et al (2019, p. 6, 8) found that 'employers who have ever employed persons living with other forms of disability had higher odds of employing persons with mental disabilities compared to those who have never employed them', which they suggest may be due to their experiential knowledge. This suggested to them that 'facilitating direct contact with employers who hire persons with mental disabilities could be key in striving for equal employment opportunities' through their sensitisation of other employers without prior experience (Ebuenyi et al, 2019, p. 8).

4. Disability stigma in Nigeria¹⁰

Within Nigerian society, the common perception is that disability issues are viewed in terms of charity and welfare. This entrenched view has a negative impact on the social inclusion of people with disabilities within the country (Lang & Upah, 2008). Persons with disabilities are often regarded as people to be pitied rather than as people who can contribute to the development of Nigeria. They face stigma and discrimination. They lack access to education, rehabilitation and employment. They are not adequately protected by legislation (Ofuani, 2011). In Nigeria, certain

¹⁰ Taken and adapted from: Thompson, S. (2019). *Nigeria Situational Analysis*. Disability Inclusive Development and Thompson S. (2019). *Nigeria Situational Analysis*. Inclusion Works.

disability types may be more stigmatised than others. Mental illness is highly stigmatised, and symptoms are hidden or denied (Smith, 2011).

Negative perceptions about children with disabilities in Nigeria were found to be related to a curse from God (due to gross disobedience to God's commandments); ancestral violation of societal norms (e.g. due to stealing); offenses against gods of the land (e.g. fighting within the society); breaking laws and family sins (e.g. stealing and denying); misfortune (e.g. due to marriage incest); witches and wizards (e.g. society saw them as witches and wizards); adultery (a major abomination); a warning from the gods of the land (due to pollution of water and the land); arguing and fighting with the elders (a societal taboo); misdeed in a previous life (such as stealing); illegal or unapproved marriage by the societal elders (arguing and fighting against the elderly advice in marriage); possession by evil spirits (due to gross societal disobedience); and many others (Eskay et al, 2012; DSPD, 2016, p. 5). However, disability is sometimes thought to be due to simple misfortune (DSPD, 2016, p. 5). Traditional negative beliefs about leprosy in Nigeria include that 'leprosy is caused by supernatural forces or as a result of a witchcraft curse pre-empted by the breaking of some form of social taboo (for instance, having sex with a menstruating female)' (Mostert, 2016, p. 14). Mostert (2016, p. 14) finds evidence that the stigma attached to leprosy 'is higher among Nigerian Christians who generally perceive leprosy as a punishment for sin, and lower among Muslims who accept leprosy as being part of God's will'. Etieyibo and Omiegbe (2016) argue that there is a paucity of evidence from Nigeria that focuses on disability and the role that religion, culture and beliefs play in sustaining discriminatory practices against persons with disabilities. Many exclusionary practices are either embedded in or sustained by religion, culture and beliefs about disability. Persons with disabilities are the victims of various discriminatory actions including the trafficking and killing of people with mental illness; oculocutaneous albinism and angular kyphosis; the rape of women with mental illness; and the employment of children with disabilities for alms-begging.

Drawing on a number of sources, Eskay et al (2012) found that in Nigerian society, children with disabilities have been incorrectly understood, and this misunderstanding has led to their negative perception and treatment. Overcoming negative attitudes and misunderstandings about disability were the basic problems affecting children with disabilities. Eleweke and Ebenso (2016) found attitudinal barriers existed when individuals with disabilities were applying for admission into schools. Such negative attitudes could be due to misunderstanding of the nature and needs of people with disabilities or due to blatant discrimination. The latter seemed to be the case for those with stigmatised conditions such as leprosy. The attitude of teachers and school administrators was a concern raised by the participants. Public education programmes and information dissemination were undertaken to try and address this challenge (Eskay et al, 2012). There are several beliefs resulting in the negative attitudes revolving around children with disabilities in Nigeria. These beliefs cut across Nigerian society and hence have a similar impact on the citizens' attitudes on learners with disabilities. A study involving students at an inclusive secondary school in Nigeria found that in general attitudes of students without disabilities towards students with disabilities were positive. Being female and having interpersonal contact was associated with positive attitudes (Olaleye et al, 2012).

Disability stigma and employment

Persons with disabilities are especially vulnerable to discrimination and disadvantage in employment in Nigeria, experiencing unequal employment opportunities, limited rights to work and low job security. Most employers are reported to be uncomfortable employing persons with disabilities due to the conviction that they will be unable to perform their roles and/or that it would be too expensive due to fear and stereotyping (Ofuani, 2011). Many employers are concerned

about productivity and influenced by negative stereotyping (Ofuani, 2011). Eleweke and Ebenso (2016) also found that even educated people with disabilities who meet the necessary requirements for employment may struggle to secure a job in Nigeria due to people's negative attitudes toward those with disabilities (see also Ofuani, 2011). They gave examples of varied experiences regarding barriers in the workplace and attitudes of their colleagues without disabilities. The attitude of colleagues made a significant impact on the work performance of people with disabilities. A study involving 56 people with physical disabilities in Rivers State reported that people with disabilities who are in work, experience negative societal perceptions being expressed towards them within the workplace. Almost 70% of respondents reported experiencing cases of humiliation at work due to their disability (Ihedioha, 2015).

A study by Ihedioha (2015) that focused specifically on the experiences of people with physical disabilities in Rivers State reports that the lack of people with disabilities who reach management level within organisations. This is possibly explained by negative attitudes towards people with disabilities. There were accounts of people with disabilities stereotyped into certain jobs (Eleweke & Ebenso, 2016). For instance, large corporations tend to put blind people in call centres regardless of their education and training. People with disabilities were sometimes reported to be employed as token gestures.

Women with disabilities may encounter more obstacles than could be attributed to gender inequalities in Nigeria, resulting in double discrimination (Eleweke & Ebenso, 2016). For example, participants in a study suggested that women with disabilities might encounter additional problems in finding employment either because of the patriarchal society or because of the pressures on firms to present attractive images (Eleweke & Ebenso, 2016).

Tackling disability stigma

Some efforts have been made to tackle disability stigma in Nigeria. As mentioned above, an e-intervention in Kenya and Nigeria in 2016, that involved showing over 1000 participants a 6-minute film designed to increase awareness of intellectual disability and its causes, and to challenge stigmatising beliefs commonly found in African countries, resulted in positive changes in attitudes, while there were no changes amongst participants who had watched the control film (Odukoya & Chenge, 2017). The films used a combination of education and indirect contact to provide factual information about intellectual disability and provide first-hand accounts of the lives of people with intellectual disabilities (Odukoya & Chenge, 2017). Data was collected at three time points (baseline, immediately post-intervention and at one month follow-up) using attitudinal questionnaires (measuring cognition, affect, and behavioural intentions) to measure the impact of the film on attitudes (Odukoya & Chenge, 2017).

Etieyibo and Omiegbe (2016) argue that the Nigerian government needs to introduce legislation that targets cultural and religious practices which are discriminatory against persons with disabilities as well as protecting the interests of persons with disabilities. The Discrimination Against Persons with Disabilities (Prohibition) Act (2018) does make discrimination of persons with disabilities illegal, but it is not yet clear how this law will be enforced and how effective it will be. In January 2019, the Discrimination Against Persons with Disabilities (Prohibition) Act (2018) was signed into law (Ewang, 2019).

5. Disability stigma in Uganda¹¹

Due to limited awareness about disability among communities, persons with disabilities continue to face both stigma and discrimination leading to their limited participation in all aspects of life (UHRC, 2016, p. 3; NUDIPU, 2014, p. 7). The Ministry of Gender Labour and Social Development (MGLSD, 2016, p. 27) notes that people with severe disabilities are stigmatised and often deprived of resources even within their own families. Aley's (2016, p. 14) study¹² in Uganda (and Kenya) also found that respondents felt that attitudes to disability in their community were overwhelmingly negative due to 'harmful traditional beliefs and misconceptions about the causes and nature of disability and about what roles and rights persons with disabilities can have in society'. Many communities believed that disability was a curse resulting from transgressions of former generations in the family (Aley, 2016, p. 14). Wrongdoings of ancestors blamed for disability are usually placed on the mother's side of the family rather than the fathers, while mother's sins or promiscuity are more often seen to be a cause of disabilities than father's actions (Aley, 2016, p. 15). Some communities believed that people became disabled because they had caused accidents and not been properly cleansed (Aley, 2016, p. 14). Others, that that it is due to demonic possession and that people with disabilities are not really human (Aley, 2016, p. 15). On the other hand some community members refer to disability in the context of the teachings of their faith and frequently viewed persons with disabilities more positively and as individuals who should be allowed to take their place in the community and be more socially included (although others believe that God imposes disability as a punishment or to prevent them from sinning) (Aley, 2016, p. 20).

People with disabilities are more likely to experience violence (47%) than people without disabilities (39%) (Leonard Cheshire, 2018, p. 63; UBOS, 2018, p. 30-32). Women and girls with disabilities are noted to face double discrimination and be at higher risk of abuse, neglect, maltreatment and exploitation (MGLSD, 2016, p. 27; CRPD, 2016, p. 2; MHU & MDAC, 2016, p. 4). Relationships between people with disabilities or between someone with a disability and someone without a disability are frequently regarded by others with suspicion, mistrust, and ridicule, and there are myths about the perceived benefits of having sex with people with disabilities (Aley, 2016, p. 22, 23, 31). Disabled children may be seen as a curse and if they are a girl, they may be denied food, education and health care (Nyombi & Kibandama, 2014, p. 250). Stigma and shame can lead to caregivers of children with disabilities hiding them away or forbidding them to take part in social activities, including because they want to protect them from such attitudes (DSPD, 2016, p. 6). In addition, there is a belief that families can gain wealth in exchange for the intellect or health of one of their children. This can result in assumptions that a family with a disabled child, particularly a child who is intellectually disabled, is greedy and ruthless, having used witchcraft to trade their child's intellect for prosperity (Groce & McGeown, 2013, p. 13). Wealthier families appeared to be particularly anxious to hide their children with disabilities as a result, although in other cases more affluent social classes were 'more likely to support their children with disabilities properly and to promote their education and social inclusion, rather than hiding them away or believing in harmful traditional practices' (Groce & McGeown, 2013, p. 13-14; Aley, 2016, p. 16). The Committee on the Rights of Persons with Disabilities also notes that it is concerned about 'persisting discrimination against persons with disabilities, including in particular persons with albinism, persons with intellectual and/or

¹¹ Taken and adapted from Rohwerder, B. (2019). *Uganda Situational Analysis*. Inclusion Works.

¹² Qualitative participatory action research in Uganda and Kenya with service providers and key responders. Involved 52 individual interviews and 9 focus groups.

psychosocial disabilities, and on other grounds, such as gender identity and sexual orientation' (CRPD, 2016, p. 2). It notes that 'persons with psychosocial and/or intellectual disabilities as well as persons with albinism and deaf-blind persons are disproportionately affected by stigma, which limits their access to education, health and employment' (CRPD, 2016, p. 3; see also MHU & MDAC, 2016, p. 4).

The 2017 Functional Difficulties Survey found that 12.9% of females felt discriminated against or harassed on the basis of disability in the previous 12 months; with 16.9% of adult males, 19.4% of girls and 12.9% of boys also reporting discrimination or harassment on the basis of disability (UBOS, 2018, p. 21). Persons with a deformity, with intellectual and/or psychosocial disabilities, and dwarfs/little people were more likely to be discriminated against than people with other types of impairments (UBOS, 2018, p. 20). In addition, people with disabilities report being discriminated against in social life, especially girls with disabilities (16.3% compared to 12.9% of boys); with 12.3% of adult men with disabilities reporting discrimination in social life compared to 7.9% of women (UBOS, 2018, p. 46). One in four people with disabilities, both men (22%) and women (25%), have experienced sexual violence, while 48% of women with disabilities and 51% of men with disabilities had experienced physical violence (UBOS, 2018, p. 30-31). This varied depending on the region, with spatial analysis of experiences of sexual violence by persons with psychosocial/intellectual disability showing that 'South Buganda (45%) West Nile (39%) and Bukedi (31%) regions had the highest percentage of sexual violence, while Busoga, Bugisu and Kampala sub regions had the lowest rates of less than 10%' (UBOS, 2018, p. 30). West Nile (82%), Kigezi (75%) and North Buganda (75%) also had the highest percentage of the adults with psychosocial/intellectual disabilities reporting that they had ever experienced physical violence (UBOS, 2018, p. 31).

In general, there are spatial differences in the experiences of discrimination of people with disabilities in Uganda. People with disabilities in the sub regions of Bukedi (Eastern region) (15.7% aged 18 and over), West Nile (Northern region) (14.9% aged 18 and over), South Buganda (Central region) (12.7% aged 18 and over), and Lango (Northern Region) (11.5% aged 18 and over) have been particularly affected (UBOS, 2018, p. 57). In total 27.5% of 5-17 year olds with disabilities and 41.4% of persons with disabilities aged 18 and above had experienced unfair treatment (UBOS, 2018, p. 57).

Disability stigma and employment

Research conducted in 2015 found also that the perceptions about and attitudes towards persons with disabilities within the general society, leading to discrimination and stigmatisation, were a significant barrier for formal employment of persons with disabilities (DPOD-NUDIPU, 2016, p. 17, 20; FUE & NUDIPU, 2017, p. 5; Rubangakene et al, 2016, p. 23). People with disabilities are routinely discriminated against in the recruitment and selection process and are liable to exploitation at work, often earning less than other employees without disabilities (Nyombi & Kibandama, 2014, p. 255; NUDIPU & UMWA, 2018, p. 1). A 2012 study with 123 participants found that persons with disabilities who were formally employed were employed in the jobs at the lowest tier of organisational hierarchy (Bekoreire et al, 2012, p. 6; see also ADD, 2011, p. 7).

Research conducted in 2015 found that the perceptions about and attitudes towards persons with disabilities by employers, leading to discrimination and stigmatisation, were a significant barrier for formal employment of persons with disabilities¹³ (DPOD-NUDIPU, 2016, p. 17, 20;

¹³ This reflects earlier research carried out in 2006 with 16 private and 2 public sector employers (Hartley et al, 2017, p. 25). In addition, it was the third highest limiting factor (14.6%) for the employment of persons with

FUE & NUDIPU, 2017, p. 5; Rubangakene et al, 2016, p. 23; NUDIPU & UMWA, 2018, p. 1; Khamisi et al, 2017, p. 12; ADD, 2011, p. 21). The Assistant Commissioner of Employment Services, for example, noted that 'persons with disabilities are often perceived as not productive and since private companies are profit driven employing persons with disabilities are not attractive' (DPOD-NUDIPU, 2016, p. 17; FUE & NUDIPU, 2017, p. 13). In addition, there is an assumption that some jobs would be too challenging for people with disabilities as a result of their impairment type or that they may be involved in accidents leading to further disability (FUE & NUDIPU, 2017, p. 13-14; Hartley et al, 2017, p. 26; ADD, 2011, p. 22). Having low expectations of persons with disabilities' qualities and experience means some employers limit their opportunities to demonstrate their potential and abilities (ADD, 2011, p. 22; Ahaibwe et al, 2019, p. 36, 38). General lack of awareness of disability and legislation in relation to it by HR Managers and CEOs, as shown above, was also flagged as an issue (DPOD-NUDIPU, 2016, p. 20-21; ADD, 2011, p. 38-39). In addition, the general understanding of disability of clients and colleagues could be a challenge for people with disabilities (FUE & NUDIPU, 2017, p. 13; Bekoreire et al, 2012, p. 7). Research in 2006 also found some employers giving 'ugly physical appearance' as a reason for not employing persons with disabilities (Hartley et al, 2017, p. 26). The myths surrounding employing persons with disabilities often result from lack of interaction and experience working with them on the part of employers (Kahmisi et al, 2017, p. 12). People with disabilities were found to tend to only get employed if they were recommended or referred by someone influential (Ahaibwe et al, 2019, p. 36).

As a result of stigma and discrimination, people with disabilities have faced abuse and discrimination at work, with 38% of adolescent respondents in a 2010 survey by the African Child Policy forum (ACPF) revealing that 'they had been attacked and insulted by fellow workers because of their disability, and 64% felt that they were treated unequally by their employers' (ACPF, 2011, p. 52; see also FUE & NUDIPU, 2017, p. 13; Bekoreire et al, 2012, p. 5, 7). Abuse ranges from psychological to sexual abuse (Bekoreire et al, 2012, p. 6). The 2017 Functional Difficulties Survey found that 14% of men with disabilities and 9% of women had been treated unfairly in finding a job; 12% of men with disabilities and 6% of women have been treated unfairly in keeping a job; and 14% of men with disabilities and 11% of women with disabilities had been dismissed from a job as a result of acquiring a disability (UBOS, 2018, p. 45). Some research by NUDIPU (2014, p. 19) also found that the 'majority of the people that become disabled while at work [we]re dismissed and ... unable to benefit under the provisions of the law on compensation'. On the other hand, 33% of people with disabilities reported being treated more positively in employment (UBOS, 2018, p. 45).

A further barrier to employment was found to be low self-esteem and self-confidence of persons with disabilities as a result of experiencing discrimination and stigmatisation (DPOD-NUDIPU, 2016, p. 18; Ahaibwe et al, 2019, p. 35). Discrimination, together with limited access to formal education and a lack of awareness of rights and entitlements, was found to lead to a vicious cycle of low self-esteem and lack of motivation to work or engage in society amongst people with disabilities, which was felt to be more of an issue than the impairment itself (Ghore, 2016, p. 8-9). Both employers and DPO representatives also felt that persons with disabilities were not applying for jobs in the formal labour market as many had never been encouraged to see themselves as employees and never been presented with the same career development opportunities as their non-disabled peers by their families, the education system, and employers (DPOD-NUDIPU, 2016, p. 18; Ahaibwe et al, 2019, p. 38). The 2017 Functional Difficulties

disabilities mentioned in the 2012 study (Bekoreire et al, 2012, p. 4). However, when it came to looking at challenges in the work place, negative attitudes towards them was the main challenge at 40.7% (Bekoreire et al, 2012, p. 5).

Survey found that 26% of men with disabilities and 21% of women had stopped themselves from applying for a job (UBOS, 2018, p. 45).

ADD (2011, p. 22) also note that discrimination by families affects the job opportunities of persons with disabilities.

Tackling disability stigma

Aley (2016, p. 14, 16) found that respondents reported that attitudes among professionals in Uganda (and Kenya) were improving and more progressive ideas about disability are beginning to be accepted, especially amongst educated and economically mobile groups, although they often qualified this observation by stating that it will still take a long time for 'the community' to change their negative attitudes. Teachers, particularly special education teachers, were viewed as being very important in influencing attitudes for the better amongst parents (Aley, 2016, p. 16). Aley (2016, p. 18) found that contact in schools, especially where pupils with disabilities had done well and were positive role models, helped to improve attitudes towards disability. Respondents also noted that progressive government policy had helped to gradually change attitudes towards disability (Aley, 2016, p. 20-21).

6. Interventions to reduce disability stigma¹⁴

False perceptions and beliefs about disability are often difficult to overcome, but they can change and evolve over time, especially when interventions aimed at addressing disability stigma are implemented (DSPD, 2016, p. 5; Groce & McGeown, 2013, p. 8). Interventions aimed at addressing disability stigma in developing countries have been aimed at the intrapersonal and familial level; the interpersonal level; and the structural level. Approaches to stigma reduction can involve contact, protest and education (Stuart et al, 2012, p. 17; NASEM, 2016). However, it should be noted that very few efforts at raising awareness and combatting stigma have been formally evaluated and evidence to support stigma interventions has been found to be sparse and weak (Scior et al, 2015, p. 6; Cross et al, 2011b, p. 63; Sheehan & Ali, 2016, p. 106). Multipronged efforts, coordinated across all levels, are likely to be more powerful (Stuart et al, 2012, p. 126; Cross et al, 2011b, p. 68). Tackling disability stigma is also challenging because reactions to it are compounded by other social attitudes (to women, ethnic and religious minorities) and by poverty, which needs to be taken into account (McConkey et al, 2016, p. 180). Approaches also need to be tailored to the variations in understanding and perceptions of disability that exist within and across countries, and to take advantage of local opportunities as they arise (McConkey et al, 2016, p. 180; Stuart et al, 2012, p. 42). One size does not fit all and anti-stigma efforts must also be locally grounded and carefully targeted to build on religious, moral, and social frameworks of the local context (Stuart et al, 2012, p. 126).

Scior et al (2015, p. 6) found that while there was a lot of work aimed at raising awareness about disability generally, 'many of these appeared to be based on the implicit assumption that raising awareness would result in more positive attitudes and a reduction in discriminatory behaviour', rather than actively aimed at changing behaviour. McConkey et al (2016, p. 180) suggest that the biggest challenge in tackling stigma may be in getting beyond changing attitudes to changing behaviour (see also Stuart et al, 2012, p. 17). Efforts to address stigma need to use a combination of methods that address its different component parts: problems of knowledge

¹⁴ Expanded and adapted from: Rohwerder, B. (2018). *Disability stigma in developing countries*. K4D Helpdesk Report 312. Brighton, UK: Institute of Development Studies.

(ignorance), problems of attitude (prejudice), and problems of behaviour (discrimination) (Cross et al, 2011, p. 73). Stuart et al (2012, p. 128) go beyond this to argue that the need is also to target the social structures, and the power relationships that erect barriers to stigmatised groups full and effective social participation.

Interventions at the intrapersonal level

'Interventions at the intrapersonal level focus on the persons affected by stigma, and aim to help them overcome the negative consequences of stigmatisation, such as self-stigma' (Werner & Scior, 2016, p. 130). Interventions at the intrapersonal level include self-help, advocacy and support groups, which have generally been found to be effective to some extent (Mostert, 2016, p. 18; Bond DDG, 2017, p. 3, 5). 'Reframing experiences in a positive way, or focusing on strengths rather than limitations, can help individuals maintain self-esteem and protect against self-stigma' (Sheehan & Ali, 2016, p. 104). The empowerment of people with disabilities is especially important for overcoming internalised stigma and stigma more generally (DSPD, 2016, p. 8; Stuart et al, 2012, p. 8). Leaders or self-advocates with disabilities 'can, through their work and participation, serve as role models of inclusion, helping other persons with disabilities to overcome internalised stigma and changing negative perceptions that may exist within communities' (DSPD, 2016, p. 8). Thus, stigma reduction efforts could include teaching self-advocacy skills to people with disabilities; providing medical and psychosocial counselling to people with disabilities to increase their self-help and self-advocacy skills; and conducting emancipatory and participatory research, whereby people with disabilities have more prominent roles in the research process (Mostert, 2016, p. 21).

Meaningful roles

As in many cultures one's human status is judged by the extent to which people can participate in valued activities within that society, the participation of people with (intellectual) disabilities in family and community life is important in challenging negative attitudes (McConkey et al, 2016, p. 190). Mostert (2016, p. 23) also suggests that the status of people with disabilities could be improved through efforts at socio-economic rehabilitation which empowers people with disabilities to engage in economic activities that enhances their lives and allows them to provide for themselves and even for others (Mostert, 2016, p. 23). In rural agrarian societies there are many livelihood activities someone with mild to moderate intellectual disabilities could participate in if prepared, for example (McConkey et al, 2016, p. 190). Skills training for people with disabilities is reported to help combat self-stigma and by demonstrating the skills of people with disabilities it can also address negative societal attitudes in the wider community by showing that people with disabilities can sustain themselves and earn money (Bond DDG, 2017, p. 6). Having other meaningful roles, such as being a mother, or a member of a club can also 'help to act as a buffer against the emotional consequences of stigma' (Sheehan & Ali, 2016, p. 104).

Interpersonal interventions

Interpersonal interventions target social interactions between stigmatised and non-stigmatised individuals, and generally involve education (aiming to challenge inaccurate stereotypes by providing factual information) or contact (encouraging positive interactions between the public and persons with disabilities) (Werner & Scior, 2016, p. 132; Mostert, 2016, p. 18). Education interventions were found to have had mixed efficacy, while contact has shown promise as a stigma reduction strategy, especially if it starts at an early age (Mostert, 2016, p. 18; Werner & Scior, 2016, p. 134, 142; McConkey et al, 2016, p. 190). Evidence suggests that it might be most

useful to combine contact-based approaches with education (Werner & Scior, 2016, p. 136; Cross et al, 2011b, p. 64; NASEM, 2016, p. 74).

Role of families

Parents and families have been central in improving perceptions of persons with (intellectual) disabilities and in the fight against negative attitudes and discrimination (Werner & Scior, 2016, p. 132). The experiences children with disabilities have within their families can help to 'build the resilience of the child to bolster their identity in the face of stigma' (McConkey et al, 2016, p. 181). However, few reports examine the effects of family-based approaches to tackling stigma (Werner & Scior, 2016, p. 132).

Ways in which families of children with disabilities can tackle stigma include actively nurturing their child's development; including them in the community; spreading information to counter myths and superstitions about disability; and advocating on their behalf (McConkey et al, 2016, p. 185-187). Acceptance within communities depends on the relationships people forge with their peers which is built up through participation in schooling, sports and religious activities, which parents can enable their children's participation in (McConkey et al, 2016, p. 190). Myths and superstitions persist because they go unchallenged which is why many parents' associations place such an emphasis on giving parents information about disabilities so that they in turn can pass this information onto others, especially in relation to their own child (McConkey, 2016, p. 187).

McConkey et al (2016, p. 186-187, 191) warn that sustaining these actions in the face of rejection and intransigence requires a vast amount of physical and emotional energy from parents and they need allies to maintain their resilience. In Africa, mothers frequently draw on their faith in God to provide them with resolve and resilience, while meeting other parents of children with disabilities also provides much needed emotional support along with informational and practical support (McConkey et al, 2016, p. 186). Families efforts need to be 'reinforced by legal rights, national policies that are enforced and changes in discriminatory practices of professionals and services to name but a few' and families should not be blamed for the stigma their relative experiences (McConkey et al, 2016, p. 190-191).

Parent and friends' associations can be an important strategy for addressing stigma in developing countries (McConkey et al, 2016, p. 188-190). International experience has shown the value of parent associations in changing perceptions within families and communities and providing information to counter ignorance and misrepresentation, as well as providing emotional and practical support (McConkey et al, 2016, p. 188; see also Aley, 2016, p. 18). Associations can be grown with support from sympathetic professionals such as community-based rehabilitation workers and national parent associations (McConkey et al, 2016, p. 188). However, they are not without their difficulties and shortcomings – rural families may struggle to have the time to access them, and professionals have an important role to play in identifying the support that families need, making use of available community resources rather than expensive programmes (McConkey et al, 2016, p. 188-189).

Education

Educational anti-stigma interventions aim to correct misinformation or contradict negative attitudes and beliefs by presenting factual information about the stigmatised condition (NASEM, 2016, p. 69; Werner & Scior, 2016, p. 132). Generally, they are aimed at combating public stigma, however educational interventions have also been found to be helpful in reducing self-stigma when delivered as part of cognitive and behavioural therapy (NASEM, 2016, p. 70).

NASEM's (2016, p. 70-71) review of anti-stigma interventions, notes that 'evidence is mixed on the effectiveness of educational interventions in changing public stigma in a significant and lasting way', especially in relation to changes in behaviour.

'Stigma-reduction educational programmes must be carefully matched to the unique culture, community, and mind-set of the population to which it is applied' (Mostert, 2016, p. 20). It has not been enough to simply educate people about the true medical causes of impairments to reduce stigma without taking into account the local social and normative nuances, as stigma is not just a result of ignorance (Mostert, 2016, p. 20; Cross et al, 2011b, p. 65). Sometimes, medically accurate information can have unintended and stigmatising consequences, as has been the case with some mental illness stigma interventions which ended up 'unintentionally drawing attention to the "differentness" of mentally ill people and diverting attention from the possibility of recovery' (NASEM, 2016, p. 71).

DSPD (2016, p. 9) suggests that inclusive and accessible human rights education in schools, which addresses specific harmful beliefs about disability in that culture, can be an important tool for combating stigma and discrimination against people with disabilities.

Werner and Scior (2016, p. 132) question the extent to which efforts to promote inclusion and more positive attitudes through educating through social media and disability organisations' programmes reach audiences who are not already positively inclined towards people with (intellectual) disabilities. Furthermore, their impact on attitude change has rarely been empirically studied.

Other educational interventions that have been more frequently evaluated have attempted to challenge misconceptions and increase knowledge and awareness through brief online films, university based lecture programmes, educational vignettes; aimed especially at students and service provider staff (Werner & Scior, 2016, p. 133). Studies in developing countries have found that while these educational interventions have been useful in increasing knowledge, their impact on (intellectual) disability stigma is frequently short-lived and of limited magnitude (Werner & Scior, 2016, p. 134).

Celebrations of people with disabilities and their contributions to society at the national or local level, for example the International Day of Persons with Disabilities or other relevant days of celebration, such as the International Day of the African Child and the Day for International Albinism Awareness, can also be used to overcome false beliefs (DSPD, 2016, p. 9). It is important however that 'such initiatives serve to counter stereotypes and not create new ones (for example, they should not be used to invoke pity or purely to inspire persons without disabilities)' (DSPD, 2016, p. 9).

Contact

Often people with stigmatised conditions have little meaningful contact with those without these conditions and this lack of contact fosters discomfort, distrust and fear (NASEM, 2016, p. 73). Contact interventions aim to overcome this divide and facilitate positive interaction and connection (NASEM, 2016, p. 73). Researchers have advocated for 'interpersonal contact with members of stigmatised groups as the most effective stigma reduction strategy', especially if it starts at an early age (Werner & Scior, 2016, p. 134, 142; McConkey et al, 2016, p. 190; McConkey, 2018, p. 6; Parnes et al, 2013, p. 30). Contact based interventions are aimed at reducing public stigma but 'have been shown to benefit self-stigma by creating a sense of empowerment and boosting self-esteem' (NASEM, 2016, p. 73).

Contact can be in person or indirectly (e.g. through films or internet) (Werner & Scior, 2016, p. 142; NASEM, 2016, p. 73). Evidence from other fields suggest that exposing people to a variety of individuals who strongly disconfirm stereotypes is likely to be most effective way to challenge stereotypes (Werner & Scior, 2016, p. 142). Involving people with (intellectual) disabilities in delivering attitude change interventions is likely to lead to more positive outcomes (Werner & Scior, 2016, p. 143). 'Contact-based interventions need to be carefully planned to minimise the risk of unintended, adverse consequences' from a negative experience (Werner & Scior, 2016, p. 142).

Community level interventions

At the community level, interventions aim to increase knowledge about impairments and address stigma within specific communities (Mostert, 2016, p. 18). Mostert (2016, p. 18) finds that the literature on community-based rehabilitation, which uses community development to rehabilitate and equalise opportunities for the social integration of people with disabilities, provides 'only vague indications that community-based rehabilitation (CRB) engenders positive outcomes for people with disabilities'. Reports by NGOs find that CRB efforts in Togo which included communication and educational tools to raise disability awareness, such as training manuals, posters, documentary films and T-shirts, resulted in parents who had previously denied having a child with disabilities acknowledging their child publicly. These efforts also resulted in cases of abuse and discrimination against children with disabilities becoming less common in these targeted communities (Bond DDG, 2017, p. 6; Parnes et al, 2013, p. 33).

Some disabled people's organisations (DPOs) have found that by working within communities they were able to transform negative attitudes and harmful practices in those communities into more positive perceptions (DSPD, 2016, p. 5). For example, a study conducted by the African Child Policy Forum in Ethiopia found that the presence of active DPOs or disability-inclusive NGOs at community level resulted in major positive differences in attitudes towards children with disabilities (DSPD, 2016, p. 9).

Other strategies especially suited to developing countries identified by McConkey et al (2016, p. 188-190) include:

- *Village gatherings*: parents associations and other advocacy groups have made use of village or community gatherings to communicate their messages on intellectual disabilities in a way that harmonises with local cultural values and activities (McConkey et al, 2016, p. 189). They use drama, songs, and speeches from invited dignitaries tailored to their particular culture with the aim of nurturing a pride in disability in families and in local communities (McConkey et al, 2016, p. 189).
- *Support from community leaders*: opinion leaders within communities (such as village chiefs and elders, traditional healers and religious leaders, elected politicians and officials) are key allies for disabled people and their families wishing to bring about change (McConkey et al, 2016, p.189). Building personal relationships seems an effective means of gaining their support, and engaging with leaders who have a relative with a disability can be especially fruitful (McConkey et al, 2016, p. 189). Support from community leaders can be crucial when it comes to removing discriminatory practices (such as school exclusions or charges levied by taxis for transporting people in wheelchairs) (McConkey et al, 2016, p. 189-190).

It is important to note that, although the role of traditional and religious leaders in combatting stigma is important as many families turn to them, they often lack knowledge of the causes of

disability and fall back on supernatural explanations (McConkey et al, 2016, p. 190; Mostert, 2016, p. 23). In this case they may actually perpetuate damaging myths, stereotypes and fear of disability, and effort needs to be made to reduce the influence of those who do so (Mostert, 2016, p. 24). If traditional and religious leaders accepted other explanations about the causes and nature of disability, they could instead contribute positively to reducing stigma instead of reinforcing it (McConkey et al, 2016, p. 190).

Interventions at the government/institutional level

'Interventions at the structural level focus on social forces and institutions through legislative action, mass media, governmental and organisational policies that aim to reach a large audience, and service delivery' (Werner & Scior, 2016, p. 138). Interventions at the institutional or organisational level may target individuals in organisations and institutions that have particular relevance to stigmatised people, such as teachers, employers or health-care providers (Cross et al, 2011b, p. 68).

Legislation and policy

Laws and policy have an important role to play in helping to avoid or remedy harmful cultural beliefs or practices and prevent discrimination against people with disabilities. Under article 8 of the UN Convention on the Rights of Persons with Disabilities, state parties are specifically required to 'undertake awareness-raising activities that address stereotypes, prejudices and harmful practices relating to persons with disabilities' (DSPD, 2016, p. 4, 12). Governments can also seek to directly address harmful practices through national policies or programmes (DSPD, 2016, p. 12).

It is also important to integrate 'disability awareness and disability services into all public institutions (for instance, schools, government departments, the public health sector, and so forth) and services for people' (Mostert, 2016, p. 21).

However, Mostert (2016, p. 20) argues that it is difficult to implement the UNCRPD if disability stigma in society is not also addressed. As a result, it is important for the government to work closely with national and regional disability organisations and NGOs and international organisations working on the frontlines in confronting stigma (Mostert, 2016, p. 20; Scior et al, 2015, p. 104). Mostert (2016, p. 20) was unable to find literature addressing the efficacy of interventions in the legal and policy arenas aimed at reducing discrimination against and enforcing the rights of people with disabilities (see also Werner & Scior, 2016, p. 139).

Media

Mass media campaigns aimed at tackling disability stigma in Western countries have been found to result in small to medium reductions in stigma, especially when they were provided in several mediums (Werner & Scior, 2016, p. 137). However, media campaigns tend to be blunt instruments, as they cannot be targeted to meet local conditions and they are confined to broad generic messages, for instance (Stuart et al, 2012, p. 128). Stuart et al's (2012, p. 165) research on the lessons learned from fighting mental health stigma suggests that the media can be more useful in efforts to communicate the nature of anti-stigma programmes and ensuring that programme materials reach a wide audience, than in changing attitudes and behaviours of populations.

In general, it is important to have positive reporting criteria around disability as without it the media can serve to cause disability stigma through negatively biased and sensational reports

about persons with disabilities (Werner & Scior, 2016, p. 141; Mostert, 2016, p. 21). Encouraging and using non-discriminatory and more positive and accurate language in the media is also important for stigma reduction (Mostert, 2016, p. 21).

McConkey et al (2016, p. 189) identified radio broadcasts as a strategy for reducing (intellectual) disability stigma which is especially suited to developing countries. Wider audiences in developing countries are best reached through radio, and drama and storytelling related to intellectual disability is well suited to radio, while oral communication in local languages is much cheaper than the production of print material (McConkey et al, 2016, p. 189). Mobile phones offer the possibility of phone-in programmes to allow callers to get information and make contact with other likeminded people (McConkey et al, 2016, p. 189).

Protest

Protest strategies are rooted in advancing civil rights agendas and present formal objections to negative representations and experiences of discrimination (NASEM, 2016, p. 76). Protest strategies are generally employed at the grassroots level by those experiencing discrimination and by advocates on their behalf (NASEM, 2016, p. 76). Targets of protest and advocacy campaigns are opinion leaders, such as politicians, journalists, or community officials (NASEM, 2016, p. 76). Their goal is 'typically to suppress negative attitudes or to remove negative representations or content' (NASEM, 2016, p. 76). Protest focusing on legislative reform often aims 'to enhance or enact protections of rights, increase access to social resources, and reduce inequalities' (NASEM, 2016, p. 76). Protest can also serve to increase public awareness and/or policy recognition of issues and concerns of the stigmatised group (NASEM, 2016, p. 76). However, protest can have unintended negative consequences, with negative public opinion sometimes strengthened as a result of the protest (NASEM, 2016, p. 77).

Advocacy

Mostert (2016, p. 23) suggests that enhancing the ability of disability advocates, persons with disabilities themselves, and their organisations to advocate for their unqualified inclusion at all levels of society is the most effective way of enhancing the social status and inclusion of people with disabilities. This can be challenging in contexts where people with disabilities have been socialised into accepting their 'lowly lot in life' although the advocacy movement in Africa is growing and becoming more vocal (Mostert, 2016, p. 21). However, Mostert (2016, p. 19) could find no literature examining the effects of advocacy to promote the rights of persons with disabilities at the national and governmental level by advocating changing laws and policies that are unfavourable to persons with disabilities or the efficacy of protest against stigma.

Reporting and documenting of abuses

Proper reporting and documenting of abuses against people with disabilities is 'essential for bringing little known practices to light and for generating advocacy strategies to combat often deeply-rooted beliefs systems that allow such persecution to continue' (DSPD, 2016, p. 11). This work is already being carried out by some DPOs and human rights organisations and should be undertaken by government bodies too (DSPD, 2016, p. 11). Journalists can also take a role in investigating and publicising abuses experienced by people with disabilities and have benefited from disability awareness training in some countries (DSPD, 2016, p. 11).

Designing a stigma intervention

Stuart et al (2012, p. 42, 126-130, 156) looked at the lessons learned from efforts to fight mental illness stigma and, amongst other things, found that:

- Anti-stigma programme objectives should be made in discussion with those affected and their families.
- Stigma interventions should be targeted at specific groups within the population (those who have a lot of contact with the stigmatised group) and the interventions should be matched to their particular needs, rather than aimed more generally.
- The stigmatised should be active participants and leaders of the anti-stigma programmes.
- Anti-stigma interventions should be tailored to local circumstances and take advantage of local opportunities as they arise.

A working group looking to design guidelines for interventions to reduce stigma created a matrix for cross-checking intervention plans based on previous understandings of stigma and stigma interventions (Cross et al, 2011, p. 77).

Table 1: A matrix for cross-checking intervention plans

Level	Components				
	Labelling	Stereotyping	Separation	Status Loss	Discrimination
Intrapersonal	How does the intervention facilitate the creation and internalisation of a new identity	How does the intervention reverse or alter internalised stereotypes	How does the intervention increase self-respect and reduce self-loathing	How does the intervention increase self-efficacy and provide opportunity for role development	How does the intervention raise self-esteem and self-assurance
Interpersonal	How does the intervention persuade others to acknowledge new identities	How will the intervention change perception from negative to positive stereotype	How will reconciliation between players be facilitated	In what ways will the intervention demonstrate the value of new role to others	What does the intervention do to promote commitment to embrace equality
Organisational/ Institutional	How does the intervention facilitate the sanctioning of changed identities	How does the intervention challenge the process of negative stereotyping	How does the intervention lead to greater participation and inclusion	How will the intervention affect power relationships to positive effect	How will the intervention ensure censure for discriminatory behaviour
Community/ Government	<p>Changing cultural norms:</p> <p>How does the intervention discourage the acceptance and endorsement of stigmatisation (community level)</p> <p>How does the intervention lead to favourable legislation (government level) and commitment to rights</p>				

Source: Cross et al (2011, p. 77)

Programme evaluation

Evaluation should be a fundamental part of anti-stigma interventions, bringing out the key components of the programme as well as things which have not worked as planned (Stuart et al, 2012, p. 167, 181). However, 'assessing change brought about by an anti-stigma programme can be a complex and difficult task' (Stuart et al, 2012, p. 170). Evaluation of change requires at least two data collection points, one before the intervention and one after, using identical instruments both times (Stuart et al, 2012, p. 171). Stuart et al (2012, p. 172, 175) suggest that the key considerations in assessing (mental health) stigma interventions effects are whether people (with mental illness) have experienced an improvement in their day-to-day lives and whether they can report fewer stigmatising experiences, rather than measuring changes in the knowledge and attitudes of programme participants.

7. References

- Ahaibwe, G., Ntale, A., & Odokonyero, T. (2019). *Labour Market Assessment Inclusion Works – Uganda Version 01 – August 2019*. Inclusion Works.
- Aley, R. (2016). *An Assessment of the Social, Cultural and Institutional Factors that Contribute to the Sexual Abuse of Persons with Disabilities in East Africa*. Advantage Africa.
- Ali, Z. (2014). *Economics of Disability in Bangladesh*. Working paper 29 November 2014. EEP/shire, Dhaka.
- Ando, M. (2017). *The right to sexual and reproductive health rights of girls with disabilities: Response by the Asian-Pacific Resource and Research Centre for Women (ARROW)*. ARROW.
- Bond Disability and Development group (DDG). (2017). *Stigma, disability and development*. Bond.
- Bunning, K., Gona, J.K., Newton, C.R., Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PLoS ONE*, 12:8, e0182214.
- CAMPE. (2011). *The status of un-served children in education Children with Disability in Bangladesh A Situation Analysis*. CAMPE, Dhaka.
- Committee on the Rights of Persons with Disabilities (CRPD). (2015). *Concluding observations on the initial report of Kenya*. CRPD.
- Committee on the Rights of Persons with Disabilities (CRPD). (2016). *Concluding observations on the initial report of Uganda*. CRPD.
- Cross, H.A., Heijnders, M., Dalal, A., Sermrittirong, S., & Mak, S. (2011). *Interventions for Stigma Reduction–Part 2: Practical Applications*. *Disability, CBR & Inclusive Development*, 22:3, 71-80.
- Cross, H.A., Heijnders, M., Dalal, A., Sermrittirong, S., & Mak, S. (2011b). *Interventions for Stigma Reduction–Part 1: Theoretical Considerations*. *Disability, CBR & Inclusive Development*, 22:3, 62-70.
- CRPD Alternative Report Platform. (2019). *Alternative Report on the Status of Implementation of the Convention on the Rights of Persons with Disabilities in Bangladesh*. Bangladesh, Dhaka.
- Danish Bilharziasis Laboratory. (2004). *Disability in Bangladesh – a situation analysis*. Danish Bilharziasis Laboratory for the World Bank.
- Department of Education (DoE). (2012). *A Policy Framework for Education- Aligning Education and Training to the Constitution of Kenya (2010) and Kenya Vision 2030 and beyond*. Republic of Kenya.
- Ditchman, N., Kosyluk, K., Lee, E-J., & Jones, N. (2016). How Stigma Affects the Lives of People with Intellectual Disabilities: An Overview. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.
- Division for Social Policy and Development (DSPD). (2016). *Toolkit on Disability for Africa – Culture, Beliefs and Disability*. UN.

- Eleweke, C., & Ebenso, J. (2016). *Barriers to Accessing Services by People with Disabilities in Nigeria: Insights from a Qualitative Study*. *Journal of Educational and Social Research*; 6 (2)
- Eskay, M., Onu, V., Igbo, J., Obiyo, N., & Ugwuanyi, L. (2012). *Disability within the African Culture*. *US-China Education Review*; B 2
- Etieyibo, E., & Omiegbe, O. (2016). *Religion, culture, and discrimination against persons with disabilities in Nigeria*. *African Journal of Disability*; 5 (1)
- Ewang, A. (2019). *Nigeria Passes Disability Rights Law*. Human Rights Watch. Accessed 11.04.2019
- Franklin, A., Lund, P., Bradbury-Jones, C., & Taylor, J. (2018). *Children with albinism in African regions: their rights to 'being' and 'doing'*. *BMC International Health and Human Rights*, 18:2, 1-8.
- GED. (2015). *Seventh five year plan - 2016 – 2020 - Accelerating Growth, Empowering Citizens*. General Economics Division (GED), Planning Commission Government of the People's Republic of Bangladesh.
- Groce, N., & McGeown, J. (2013). *Witchcraft, Wealth and Disability: Reinterpretation of a folk belief in contemporary urban Africa* (Working Paper Series: No. 30). Leonard Cheshire Disability and Inclusive Development Centre, UCL.
- Hosain, G., Atkinson, D., & Underwood, P. (2002). *Impact of Disability on Quality of Life of Rural Disabled People in Bangladesh*. *Journal of Health, Population and Nutrition*; 20 (4).
- Huda, P.S., Sarwar, R., & Imran, M. (2019). *Labour Market Assessment Inclusion Works – Bangladesh Version 01 – August 2019*. Inclusion Works.
- Huq, N., Edmonds, T., Baker, S., Busjia, L., Devine, A., Fotis, K., Marella, M., Goujon, N., & Keefe, J. (2013). *The rapid assessment of disability-informing the development of an instrument to measure the effectiveness of disability inclusive development through a qualitative study in Bangladesh*. *Disability, CBR and Inclusive Development*; 24 (3).
- Ihedioha, E. (2015). *Environmental barriers and job placement of the physically challenged in organizations in Rivers State, Nigeria*. *Global Journal of Arts Humanities and Social Sciences*; 3 (4).
- Inguanzo, I. (2017). *The situation of indigenous children with disabilities*. Policy Department, Directorate-General for External Policies, European Union.
- Jillo, A.B.A. (2018). *Statement By Hon. Abdul Bahari Ali Jillo Chief Administrative Secretary, Ministry Of Labour & Social Protection Of The Republic Of Kenya During The Eleventh Session Of The Conference Of States Parties To The Convention On The Rights Of Persons With Disabilities*. U.N.
- Kabare, K. (2018). *Social Protection and Disability in Kenya*. Development Pathways.
- Kandasamy, N., Soldatic, K., & Samararatne, D. (2017). *Southern Gendered disability reflections*. In Soldatic K, Johnson K (Eds). 2017. *Disability and Rurality: Identity, Gender and Belonging*. Routledge, UK.
- Kenya National Commission on Human Rights (KNCHR). (2016). *Compendium on submissions to the Convention on the Rights of Persons with Disabilities*. KNCHR.

- Kingiri, A., Khaemba, W., Olenja, J., Gitonga, A., Oloo, W., Nyariki, E., & Wafula, S. (2017). *Policy brief: The labour market situation in Kenya: promoting right to work and employment for persons with disabilities*. Leonard Cheshire Disability and Inclusive Development Centre, UCL.
- Lang, R., & Upah, L. (2008). *Disability Scoping Study in Nigeria*. Department For International Development, London
- Leonard Cheshire. (2018). *Disability Data Review: A collation and analysis of disability data from 40 countries*. Leonard Cheshire.
- McConkey, R. (2018). *Citizenship and people with intellectual disabilities: An international imperative?* In B. Watermeyer, J. McKenzie & L. Swartz (eds). Palgrave Handbook of Disability and Citizenship in the Global South. Palgrave Macmillan.
- McConkey, R., Kahonde, C., & McKenzie, J. (2016). Tackling Stigma in Developing Countries: The Key Role of Families. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.
- Mental Health Uganda (MHU) & Mental Disability Advocacy Centre (MDAC). (2016). *DPO and NGO information to the United Nations Committee on the Rights of Persons with Disabilities for consideration at the 15th Session*. MHU & MDAC.
- MGLSD. (2016). *SOCIAL DEVELOPMENT SECTOR PLAN (SDSP) 2015/16 -2019/20*. The Republic of Uganda.
- Mostert, M.P. (2016). *Stigma as a barrier to the implementation of the Convention on the Rights of Persons with Disabilities in Africa*. *African Disability Rights Yearbook*, 2-24.
- National Academies of Sciences, Engineering, and Medicine (NASEM). (2016). *Ending Discrimination Against People with Mental and Substance Use Disorders: The Evidence for Stigma Change*. Washington, DC: The National Academies Press.
- NGDO et al. (2015). *Current status of rights of persons with disabilities in Bangladesh: legal and grassroots perspectives*. NGDO, NCDW and BLAST, Dhaka
- Njelesani, J., Hashemi, G., Cameron, C., Cameron, D., Richard, D., & Parnes, P. (2018). *From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa*. *BMC Public Health*, 18:153.
- NUDIPU. (2014). *Alternative Report To The UN Committee Of Experts On The Implementation Of The Convention On The Rights Of Persons With Disabilities (CRPD)*. NUDIPU.
- Odukoya, D., & Chenge, W. (2017). *The Era of Digital Interventions: Combating intellectual Disability Stigma in Africa*. UCL blog.
- Ofuani, A. (2011). *The right to economic empowerment of persons with disabilities in Nigeria: How enabled?* *African Human Rights Law Journal*; 11.
- Olaleye, A., Ogundele, O., Deji, S., Ajayi, O., Olaleye, O. & Adeyanju, T. (2012). *Attitudes of Students towards Peers with Disability in an Inclusive School in Nigeria*. *Disability, CBR & Inclusive Development*; 23 (3).
- Parnes, P., Hashemi, G., Njelesani, D., Njelesani, J., Richard, D., Cameron, C., & Keachie, H. (2013). *Outside the Circle - A research initiative by Plan International into the rights of children with disabilities to education and protection in West Africa*. Plan International.

- Peters, R. (2015). *"I am not shy...so I don't have leprosy, right?" Understanding and assessing leprosy-related stigma and the effect of stigma-reduction interventions in Cirebon District, Indonesia*. De Vrije Universiteit Amsterdam.
- Power, M.J., Green, A.M., & The WHOQOL-DIS Group. (2010). *The Attitudes to Disability Scale (ADS): development and psychometric properties*. *Journal of Intellectual Disability Research*, 54:9, 860-874
- Quinn, M., Hunter, C., Sumanta Ray, S., Quadir, M., Sen, K., & Cumming, R. (2016). *The Double Burden: Barriers and Facilitators to Socioeconomic Inclusion for Women with Disability in Bangladesh*. *Disability, CBR & Inclusive Development*, 27 (2)
- Rodríguez, P., Ahern, L., Bradshaw, J., Kanter, A.S., Koiyiet, M., Levy, R., Miller, M.R., Rosenthal, E., & Wangare, F. (2018). *Infanticide and Abuse: Killing and confinement of children with disabilities in Kenya*. Disability Rights International & Kenyan Association for the Intellectually Handicapped.
- Rugoho, T., & Maphosa, F. (2017). *Challenges faced by women with disabilities in accessing sexual and reproductive health in Zimbabwe: The case of Chitungwiza town*. *African Journal of Disability*, 6, a252.
- Scior, K. (2016). Towards Understanding Intellectual Disability Stigma: Introduction. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.
- Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2015). *Intellectual Disabilities: Raising Awareness and Combating Stigma- a Global Review*. University College London.
- Sheehan, R., & Ali, A. (2016). Self-stigma in People with Intellectual Disabilities. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.
- Sightsavers. (2018). *AN ANALYSIS OF THE STATUS OF PERSONS WITH DISABILITY IN KENYA*. Sightsavers Kenya.
- Smith, N. (2011). *The face of disability in Nigeria: a disability survey in Kogi and Niger states*. *Disability, CBR and Inclusive Development*, 22 (1).
- Stone-MacDonald, A., & Butera, G. (2014). *Cultural Beliefs and Attitudes about Disability in East Africa*. *Review of Disability Studies*, 8:1, 1-19.
- Titumir, R., & Hossain, J. (2005). *Disability in Bangladesh prevalence, knowledge, attitudes and practices*. Unnayan Onneshan, Dhaka.
- TLMB. (2019). *Joint submission of The Leprosy Mission Bangladesh and Protibondhi Nagorik Shangathaner Parishad (National Network of DPOs) to the 11th Pre-Session of the CRPD Committee*.
- UBOS. (2018). *Uganda Functional Difficulties Survey 2017*. UBOS.
- Uganda Human Rights Commission (UHRC). (2016). *Submission to the Committee on the Convention on the Rights of Persons with Disabilities*. UHRC.

UN. (2019). *Committee on the Rights of Persons with Disabilities - List of issues in relation to the initial report of Bangladesh*. Published 6 May 2019

UNICEF. (2014). *Situation analysis on children with disabilities in Bangladesh*. UNICEF, Dhaka.

Werner, S. & Scior, K. (2016). Interventions Aimed at Tackling Intellectual Disability Stigma: What Works and What Still Needs to Be Done. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.

Werner, S. (2016). Measurement Methods to Assess Intellectual Disability Stigma. In K. Scior & S. Werner (eds.). *Intellectual Disability and Stigma: Stepping Out from the Margins*. Palgrave Macmillan.

Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2012). *Stigma and intellectual disability: A review of related measures and future directions*. *Research in Developmental Disabilities*, 33, 748–765.